

**Do I have to take part?**

You don’t have to take part, it is up to you. If you decide to take part you and your parents will be asked to sign a form saying you agree to take part. If at any time you don’t want to do the research any more, just tell your parents, doctor or nurse. They will not be cross with you.

The information collected will be kept a secret. We will keep your name locked away in the study office to help check information, but will not put your name on a computer.

**If you would like to know more** you can ask one of the doctors or nurses looking after you or you can contact Professor Ian Bruce at the University of Manchester:

0161 2755993 ian.bruce@manchester.ac.uk

The results of the research will be written about in a medical journal, but not for a few years. Your doctor will be able to tell you how the research is going. No-one will know that your information is included in the research.

The study will be run by the British Isles Lupus Assessment Group and the Arthritis Research UK Epidemiology Unit at the University of Manchester. Your hospital department will get a little bit of money to help pay for the time your doctor takes to fill in the information about you.

Thank you for helping with this study. If you decide to take part in the study please keep this information sheet so that you can look at it in the future

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We want to invite you to take part in a research study. Before you decide, it is important for you to understand what it is and what happens. Please read this leaflet carefully and talk to other people about it if you want. Ask us if you don’t understand anything. Take time to think it over

**What is the study for?**

Some new medicines, called biological therapies, and other medicines like azathioprine, mycophenolate mofetil or cyclophosphamide are being used to treat people with lupus.

We would like to know more about how these and other medicines work, and if they have any bad effects as well as good ones. A group of doctors, nurses and other people caring for people with lupus have set up a list on a computer to collect this information about people like you with lupus. We would also like to know how you are over the next 3 years or so.

**Why have I been chosen?**

You have been chosen to be invited because you have lupus and are taking either a new medicine or the usual medicine for your lupus.

**What information will we collect from you?**

The study will collect information about you, your lupus, and medical treatment and how well you are. Information about your health and treatment will be sent to the study for at least three years.

We would like to collect an extra blood sample from you for the study at a number of different times. We will collect this blood at the same time as your usual blood tests. We would also like to collect a small sample of urine from you.

We would like you to fill in some questionnaires about how you feel and let us know in a diary any time you go to hospital or have new medicines. If you want someone to help with this that is fine.

We hope the research will help doctors to treat patients better in the future.

We will also make sure that we can trace you through your family doctor (GP) so we can find out how you are in the future.

If you or your parents have a complaint about this research study, you can complain to University Research Practice and Governance Coordinator on 0161 2757583 or 2758093 or by email to research-governance@manchester.ac.uk . Please talk to someone at your local centre if you feel you can.

What do I have to do to take part?

Your doctor will ask you if you want to take part in the study. They will answer any questions you have. If you need more time to think about it, please let them know and they will be happy to talk about it at your next appointment. If you want to take part in the study you and your parent will be asked to sign a form to show that you agree. You can change your mind at any time without saying why. Whatever you decide will not change how doctors treat you.



**Information for children & young people**

Version 4, 11/03/2011

The BILAG Biologics Prospective Cohort

